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Preserving the golden age of medicine – creating an oral history archive of early pioneers of European Paediatric Nephrology

Yincent Tse, Heather Maxwell, Alan Watson, Richard Coward, Elena Levtchenko and Martin Christian on behalf of the European Society for Paediatric Nephrology

Correspondence author:

Dr Yincent Tse, Secretary of British Association for Paediatric Nephrology and Consultant Paediatric Nephrologist, Great North Children's Hospital, Newcastle Upon Tyne NE3 4NL, UK. +44 191 2829600

Yincent.tse@nuth.nhs.uk

Heather Maxwell, Consultant Paediatric Nephrologist and ESPN 2017 Conference President, Queen Elizabeth II Hospital, Glasgow, UK

Alan Watson, Emeritus Professor of Paediatric Nephrology, University of Nottingham, UK

Richard Coward, Professor of Renal Medicine, University of Bristol, UK

Elena Levtchenko, Secretary General, European Society for Paediatric Nephrology,

University Hospitals Leuven, Belgium

Martin Christian, Consultant Paediatric Nephrologist, Nottingham Children's Hospital, UK

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Summary

The 1960s heralded an era when rapid advances in human technology led to tremendous advances in medicine. We describe how the European Society for Paediatric Nephrology (ESPN) marked its 50th anniversary by creating an oral video archive from early pioneers treating children with kidney diseases. Today's inexpensive technology democratises the ability to preserve medical history for future generations in a vivid form.

Background

2017 marked the 50th anniversary of the European Society for Paediatric Nephrology (ESPN) foundation meeting in Glasgow. It was attended by X delegates from Y countries making it the biggest ESPN meeting to date (if true!). In 1967, 36 paediatric nephrologists from 22 countries gathered to share outcomes, innovations and to collaborate to fight kidney diseases in children. Today, there are over 1500 paediatric nephrologists in Europe. 2017 was also the centenary of the world's first paediatric and adult kidney biopsies which also took place in Glasgow at the Royal Hospital for Sick Children. This was later published in Archives of Disease and Childhood in 1930, and outlined the result of a series of kidney 'decapsulation' to try to treat nephrosis, what we would today call nephrotic syndrome. A series of 19 children underwent this procedure and as part of this an open kidney biopsy was taken and examined microscopically [1].

This era heralded the beginning of paediatric subspecialisation in nephrology. In Glasgow Gavin Arneil (1923-2018) established a regional referral unit for children with kidney disease, it was the first in UK and only the third in Europe after Paris and Helsinki. Since then tremendous advances in medical, nursing and psycho-social care have been made.

Before 1960s, no child with end stage renal failure survived as neither dialysis nor transplantation was possible. Although today's treatment remains imperfect and complications still need to be intensively managed, more than 90% of children survive [2].

Several written accounts of the histories of paediatric nephrology have been collated from different geographical viewpoints, mainly about the organisation that were set up to collaborate innovations across the UK [3], Europe [4] and internationally [5]. The Wellcome History of Twentieth Century Medicine held a witness seminar about dialysis in the UK 1950-80 that included accounts from pioneer doctors, nurses and patients that included a child and her mother [6].

Video added a new dimension for viewers to understand and appreciate medical history. The 1965 inaugural episode of BBC's Tomorrow's World, a television series on new developments in science and technology showed adult patients and staff on the haemodialysis unit at the Royal Free Hospital, London with this new life extending treatment. Among those featured was a 24-year-old Robin Eady (1940-2017) stoically demonstrating how his dialysis cannulas were inserted and how the machine operated [7]. This young adult was at the time a medical student who later graduated to be a renowned dermatologist specialising in epidermolysis bullosa and became the world's longest-survivor with kidney failure.

Recording history

In preparations for the 50th ESPN anniversary conference in September 2017 through members and other European national paediatric societies, we asked volunteers to film their retired mentors / emeritus physicians between February and August 2017. Sample interview

questions were suggested but were for guidance only. Many of the pioneers we were to discover had already died; those still alive were elderly and often frail

The majority of contributors submitted videos filmed on mobile phone cameras. Submissions were transferred electronically via cloud storage platforms (e.g. Dropbox or Google Drive.) All were of usable (640x480 pixels) to broadcast quality (1920x1080 pixels) of duration between 6 to 75 minutes. The majority of interviewees spoke English with four requiring subtitling into English translations. Clips were edited for aesthetic purposes only, without any loss of content. Completed videos were uploaded onto a free publicly accessible video-sharing website (www.youtube.com/c/ESPNhistory). As of March 2018, our video repository has been viewed 5000 times.

47 videos from 12 countries were recorded. They included interviews with 34 emeritus paediatric nephrologists of whom seven attended the inaugural 1967 meeting (table). Their voices recount vividly the desperation families and children suffered when treatment was ineffective and transplant or dialysis unfathomable - followed by the era of rapid innovation. We learn from the pioneers their own personal stories of self-sacrifice, heroism and dogged persistence. Of interest to our current generation is the historical and technological context: The Iron Curtain curtailing travel, no computers, internet, emails or Medline. These pioneers matured research from personal case series to the international collaborations which have influenced the way we work today.

Table. Individuals and their country of work featured in the ESPN video oral history archive.

* denotes those who attended the first ESPN meeting in 1967.

Gavin Arneil *	UK
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Ayşin Bakkaloğlu	Turkey
Albert Bensman	France
Michel Broyer	France
Luis Callís *	Spain
Stewart Cameron *	UK
Cyril Chantler	UK
Marie Claire Gubler	France
Pierre Cochat	France
Rosanna Coppo	Italy
Alphan Cura	Turkey
Michael Dillon	UK
Alfred Drukker	Israel
Jochen Ehrich	Germany
Andreas Fanconi *	Switzerland
Marie-France Gagnadoux	France
Ayfer Gür Güven	Turkey
Enver Hasanoglu	Turkey
Christer Homberg	Finland
Ian Houston *	UK
Maya Ignatova *	Russia
Ernst Leumann	Switzerland
Chantal Loirat	France
Rita Lombaerts Van Damme	Belgium
Otto Mehls	Germany
Leo Monnens	The Netherlands
Anna Murphy	UK
Patrick Niaudet	France

Bob Postlethwaite	UK
Willem Proesmans	Belgium
Karl Schärer	Germany
Karel Van Acker *	Belgium
Alan Watson	UK
Richard White *	UK

Of the 11.8 hours of footage, we edited a 20-minute compilation video to show at the conference opening; the most useable clips being pioneers recounting patients' experiences rather than about organisation setups. We were fortunate to be joined by the aforementioned Gavin Arneil who was not only a pioneer in nephrotic syndrome but founded the major UK and international paediatric nephrology societies (4). He was to die four months later aged 94.

As part of the anniversary we also held and recorded a history symposium delivered by early pioneers which is saved in the same video repository. Topics included the start of dialysis and transplantation in children, first use of renal biopsy to understand pathophysiology, collaborative work of the ESPN and development of the multi-disciplinary team. Creating this opportunity for retired experts to reflect on 50 years of progress gave a unique wide-angled perspective. For example, we learn that parent partnership for rare disease research is not new. In 1953 a small group of parents of children suffering from nephrotic syndrome banded together to form the National Nephrosis Foundation in New York to fund researchers and find cures (5,8).

Leaving a digital footprint

Collecting oral history is important because most of this rich anecdote has never and will never be recorded in writing. Our videos record the personal experience of these pioneers of their times and through them their patients' experiences, fears, hopes and joys. Oral history has been highly effective in recording the voices and recognising the contribution of war veterans, minority communities and everyday people in various civil rights movements [9].

With today's inexpensive smartphone technology, we all carry in our pockets the ability to preserve history. We can achieve breath by collaborating internationally. We owe it to future generations to preserve a living oral history of medicine of this remarkable bygone age from those who made it happen before they all pass away.

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Competing interests:

None

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Figure. Screenshot of the oral history repository of the European Society for Paediatric Nephrology. www.youtube.com/c/ESPNhistory

